

Public Involvement in Health Priority Setting: Future Challenges for Policy, Research and Society

Williams, Iestyn; Hunter, David; Katharina, Kieslich; Littlejohns, Peter; Staniszewska, Sophie ; Tumilty, Emma; Weale, Albert

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**Public Involvement in Health Priority Setting: Future Challenges for
Policy, Research and Society**

Abstract

Purpose

The article reflects on the findings of this special issue and discusses the future challenges for policy, research and society. The findings suggest that challenges emerge as a result of legitimacy deficits of both consensus and contestatory modes of public involvement in health priority setting.

Design/Methodology/Approach

The article draws on the discussions and findings presented in this special issue. It seeks to bring the country experiences and case studies together to draw conclusions for policy, research and society.

Findings

At least two recurring themes emerge. An underlying theme is the importance, but also the challenge, of establishing legitimacy in health priority setting. The country experiences suggest that we understand very little about the conditions under which representative, or authentic, participation generates legitimacy and under which it will be regarded as insufficient. A second observation is that public participation takes a variety of forms that depend on the opportunity structures in a given national context. Given this variety the conceptualization of public participation needs to be expanded to account for the many forms of public participation.

Originality/Value

The article concludes that the challenges of public involvement are closely linked to the question of how legitimate processes and decisions can be generated in priority setting. This suggests that future research must focus more narrowly on conditions under which legitimacy are generated in order to expand our understanding of public involvement in health prioritization.

Keywords

Public participation, priority setting, legitimacy, authentic representation, equitable health coverage

Article Classification

General Review

For Review Only

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Introduction

The articles in this special issue demonstrate that public involvement in health priority setting remains a complex subject matter in which both the modes and the effects of participatory endeavours are highly contextualized. Bringing the country experiences and case studies together to draw conclusions for policy, research and society is therefore neither an easy nor straightforward undertaking. Nevertheless, at least two recurring themes emerge from the articles. An underlying theme is the importance, but also the challenge, of establishing legitimacy in priority setting. A second observation is that public participation takes a variety of forms that depend on the opportunity structures in a given national context. Given this variety the conceptualization of public participation needs to be expanded to account for the many patterns and forms of public participation. Both themes give rise to a plethora of research and policy questions on which this concluding article reflects.

Whether the focus is on the multiple and varied patterns of public participation in different countries or on the claims of tokenism in health systems with institutionalized forms of public and patient involvement (PPI), the implicit theme common to these issues is the question of legitimacy. The fundamental problem effective priority setting needs to overcome is one of legitimacy. Contestatory forms of participation emerge in the form of public protests and campaigns in most health systems at given points in time, suggesting that questions about the legitimacy of priority setting arise regardless of the presence or absence of formalized structures for public participation. In practice, the role that public participation plays in establishing legitimacy is a question of authentic representation, a concept elaborated in the following section. It is about representation because the individuals who participate will always represent one group, one opinion, one community, inter alia, and not society as a whole. The experiences brought together in this special issue suggest that we understand very little about the conditions under which representative, or authentic, participation generates legitimacy and under which it will be regarded as insufficient. Moreover, it is likely that the conditions and perceptions of legitimacy are fluid and subject to change depending on a wide range of dynamic internal and external forces.

The country experiences discussed by Slutsky et al. (2016) show that public and patient advocacy groups make their voices heard by resorting to contestatory

forms of participation in systems where institutionalized opportunities for participation are either under-developed, ineffective, or both. In Latin America, and to a lesser extent in other health systems, participatory processes exist in which patients and the public bring their individual and collective battles to court (Kieslich et al., 2016). This is happening despite the existence of formalized mechanisms through which citizens can participate in health prioritization. It implies that current structures aimed at rendering coverage decisions more legitimate are either insufficient, or are supplanted by modes of involvement that promise a more tangible and visible effect on the outcome of a coverage decision. It also suggests that institutionalized modes of public participation and informal, unconventional, contestatory patterns of participation may exist alongside each other or largely separate from one another. In either case, they are likely to have an effect on the perceived fairness and legitimacy of prioritization decisions. This paper reflects on the theme of fairness and legitimacy by offering thoughts on how public participation may contribute to addressing equity in health coverage. As we shall see, this is closely linked to the question of legitimacy that arises from a fair, or authentic, representation of the public.

The findings collated in this special issue also suggest a situation in which modes of participation such as litigation and mobilization may be viewed as more successful in influencing prioritization decisions than institutionalized modes of public involvement. If, as Weale et al. (2016) note in the introduction to this special issue, public participation is aimed at securing a decision on public policy or legal rules, the presented findings suggest that contestatory and unconventional modes of participation are more effective at securing such decisions. Kieslich et al.'s (2016) paper on public involvement in coverage decisions on new antivirals for hepatitis C shows that the formalized mechanisms of involvement seem to have had little effect on the outcome of decisions in England, the USA and Brazil. Given their clinical effectiveness, but also their high cost, it is difficult to imagine a scenario in which a decision other than to limit access to these medicines according to disease progression would have been made. This article offers thoughts on some of the current barriers to making institutionalized public participation more meaningful, or legitimate, including the urgency to convince the public of the need for priority setting in the first place.

The hepatitis C case study also indicates that the effect of formalized participatory modes may be subtle at first, but potentially wide-ranging later. The

views brought forward by public members and patient advocates highlighted a number of unresolved issues in health priority setting such as how to balance clinical innovation and budgetary concerns, which need to be addressed by policymakers and health service managers. It is imperative to reflect further on the implications of the articles' findings for policymaking and health service managers, a task to which this concluding paper turns in later sections including proposals for future research on public participation in health priority setting.

Public Participation, Health Priority Setting and Equitable Coverage Decisions

The article follows the conceptualization of public participation found in the previous articles of this special issue, that is public participation is defined as a collective activity aimed at securing a decision on public policy and legal rules through consensus or contestatory modes of participation (Weale et al., 2016). It largely excludes decision-making processes at the individual level such as shared decision-making in the clinical setting or participation in research. As Weale et al. (2016) note, this does not suggest that these forms of participation are unimportant, but because they have few implications beyond the individual patient level, they were excluded in the articles of this special issue. Nevertheless, this article suggests that research on the relevance of this special issue's findings to the field of PPI in research would provide a useful contribution to the extant literature.

The aim of priority setting in health is to build structures and develop rules that inform efficient *and* fair coverage decisions in the context of limited health budgets. Public participation in these priority setting exercises is thought to contribute to fair decision-making in manifold ways (Williams et al., 2012). While this article focuses on the role of public participation in achieving equitable decisions, it also acknowledges that this is not the only role, or benefit, of public participation. Public participation provides opportunities for more direct democratic involvement and for deliberative processes (democratic benefit); it allows for an open discussion about demands on resources within limited budgets, providing educative moments for the public who often do not have insights into the bigger picture of demands and trade-offs (educative benefit); and affords a means of decision-making that connects directly with the values of the public, thus aiming for decision-making that better reflects the public will (instrumental benefit) (Williams et al, 2012; Abelson et al.,

2003). However, given the emphasis that the literature places on the role of public involvement in bringing about fair and legitimate decisions (e.g. Daniels and Sabin, 1997), it is important to reflect upon the implications of the collated findings on questions of equity as they arise in health coverage decisions. The findings suggest that public participation does not in and of itself promote equitable decisions without important caveats.

In order to assess the potential role public participation can play in bringing about more equitable decisions in priority setting, the concept of equity, or inequity, in health is a useful starting point. Health inequity is defined as “differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust” in health (Whitehead, 1992). To define a priority setting exercise as fair in relation to health inequity would require that it either (1) provided equal access to care for equal need (horizontal equity), or (2) supported equal use of care or equal outcomes for equal need (vertical equity) (Braveman, 2006; Culyer and Wagstaff, 1993; Oliver and Mossialos, 2004). The latter requires an unequal distribution of care in favor of those most in need, whereas the former, requires ensuring access is equally available to all. This provision or support can only be provided if decision-makers have a clear understanding of the need that is to be addressed and the acceptability of solutions proposed to the populations they affect. PPI is meant to provide these understandings, so that policy is acceptable to all that it affects (Habermas, 1994).

Two models of public participation have been put forward, the consensus and the contestation models (Weale, 2016). Either model can affect health inequity, but by what mechanisms and to what degree is of particular interest. We see examples of contestation in two main forms: those that aim for universal health care, for example in the Republic of Korea (Kwon, 2003), or protests against health reform or cuts, for example in Colombia (Barrero et al., 2012) or New Zealand (New Zealand Herald, 2010), and those that aim for access to specific services or medical interventions for a particular group (Johnston, 2006). The former addresses horizontal equity, the latter has the potential to address vertical inequity, but in practice can also cause further inequity. The forced provision of a specific treatment necessarily requires the redistribution of funding within a limited budget (Matheson and Loring, 2016). It is also the case that the disadvantaged are generally less well positioned to mobilize and protest and so their health needs within a contestation model are likely to be overshadowed by others better placed to advance their interests.

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The question of better representation that was raised in the introduction (Weale et al., 2016) is a salient one when addressing health inequities in consensus models of public participation. To address health inequity in a consensus model, public participation activities need to ensure fair representation of the interests and needs of those who are disadvantaged and marginalized, where fair representation is defined as accurate, comprehensive, and authentic. Authentic representation means that the disadvantaged group stands behind the representation being made of them, and that it genuinely reflects their needs and interests. For this to be the case, the person(s) speaking for them must be an accepted champion (either from within or on behalf of the group). Comprehensive representation means the group in its diversity is represented in its entirety. Many marginalized groups are often heterogeneous. For example in New Zealand, Māori - the indigenous population - have various iwi (tribes) with different dialects (Te reo, language) and cultural practices (Tikanga), or disabled populations can have a range of disability and therefore needs and concerns. A champion to represent these groups must reflect the range of interests and needs present in the group or multiple champions are necessary. Accurate representation means that interests and views put forward are those of the group and not the imagined or extrapolated interests and views of the group, which is in part contingent on authentic representation.

An alternative to the representation by a champion(s) is community input. More costly and harder to achieve, input direct from the community through facilitated meetings provides information to guide decision-making (for an example see Oregon (Dixon and Welch, 1991)). This information however is not dialogic – it can only be gathered at one point during the decision-making process and therefore is limited in comparison to a champion who can engage and respond to ongoing discussions. It still may lack comprehensiveness depending on how well the diversity of the population engaged with the process is represented.

How to enhance democratic legitimacy (Weale et al., 2016) in consensus models of public participation also remains a concern. Collective public participation in a consensus model can take the form of legitimizing decisions (passive) or informing them (active). Legitimizing decisions may be labeled a lesser form of public involvement in that the decision-makers do not seek input per se, but rather approval for decision-making processes or decisions made based on other factors such

as expert knowledge or cost-effectiveness (Weale, 2016). This is where the need for democratic legitimacy and fair, or better, representation intersect as fair representation is required for communities to accept legitimized decisions. If the representation is seen as lacking in authenticity, then the legitimization lacks effectiveness. This was evidenced in the National Institute of Health (NIH) Consensus Conferences, which, while set up as a deliberation processes, were often a legitimizing one for clinicians (Solomon, 2015). Active public participation in a consensus model requires decision-making processes that allow fair representation throughout the process for all affected groups and particularly the disadvantaged, if aiming for provision that addresses health inequity (especially vertical health inequity). As has been argued elsewhere (Weale et al., 2016), this means that this representation is given appropriate weight in the decision-making process rather than being an adjunct to it. Given the costs of public participation activities, it is essential that representation is given appropriate consideration and that the purpose and aims of the activities are clearly defined to avoid the creation of wasteful processes (Mitton et al, 2009).

The country experiences provided in this special issue underline the challenges of fair representation in systems where active consensus models are present in the form of mini-publics, lay-members, stakeholder groups, and consumer panels. Participation in such groups requires a high level of skill and confidence. Therefore, the representative for disadvantaged groups is generally an outsider “champion”, someone who has worked with or cares about the population they represent. This, in and of itself, however does not guarantee authenticity, comprehensiveness, or accuracy in their representation. Examples of champion representation for disadvantaged populations are the Patient-Centered Outcomes Institute’s Addressing Disparity panel in the United States of America (USA), where the biographies of members show connection to their populations of interest. Similarly, the consumer advisory panel of New Zealand’s Pharmaceutical Management Agency (PHARMAC) consists of a group of individuals who could be presumed to have authentic connections to a variety of disadvantaged and marginalized groups, even though this panel operates in a mixture of active and passive consensus-based PPI roles (PHARMAC, 2016).

In summary, public participation in both its consensus and contestation models can contribute to more equitable decisions in priority setting if equity is defined as horizontal equity. Achieving vertical health equity requires fair representation of

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disadvantaged groups that is authentic, comprehensive, and accurate either through a champion or community deliberation process in an active consensus-based PPI model. However, in reality vertical health inequity is frequently addressed through contestatory forms of participation in which injustices may be voiced, and sometimes listened to, without being explicit about the effects of any resulting unequal distribution of health resources. The caveats to the role of public involvement in achieving equitable, and legitimate, decision-making are further exacerbated by the complex matter of convincing the public of the need to set priorities in health and to create more flexible mechanisms for involvement.

Public Participation, Legitimacy and Routinization in Health Priority Setting

It has been 15-20 years since Soren Holm (1998) said ‘goodbye to the simple solutions’ for priority setting and Alan Williams took issue with Rudolf Klein over the respective merits of information and institutions as the means by which to improve decisions (Klein and Williams, 2000). Yet we are barely any closer now to priority setting being a routine feature of resource allocation processes. Arguably this is principally due to a failure to persuade a broad enough constituency that limit setting is a legitimate and necessary part of the management of health systems. Despite attempts to shift the centre ground, priority setting is still defined more by technocracy than democracy. Achieving wider public engagement is both the most urgent and the most important next step for priority setting. However, it is conceptually and practically fraught.

As a field of academic study, priority setting has been heavily influenced by prescription, from disciplines including economics, ethics and decision analytics. Perhaps inevitably therefore, the ‘participation turn’ in priority setting has followed a similar path. Models such as accountability for reasonableness (A4R) and methodologies such as citizens’ juries and deliberative polling have been advocated, and much time has been spent incorporating engagement elements into more established decision support tools such as Programme Budgeting and Marginal Analysis, Health Technology Assessment, Multi-Criteria Decision Analysis, and so on.

However, in each of these tools the role assigned to the public is highly constrained in a number of areas and dimensions including the:

- Decision stage: The public are often consulted on pre-identified investment options but are rarely involved in the design of the decision-making process, setting of decision agendas and options, or final ratification of decisions.
- Scope of input: The forms of input that citizens are granted are often circumscribed. They may for example be asked to 'represent' a wider constituency or to consider incidental or secondary aspects of a decision again rather than taking a more central and equal role vis-à-vis other decision-making agents.
- Extent of influence: Public inputs are invariably considered alongside and/or weighed against other inputs understood as distinct, such as evidence and expertise. This has led to doubts over the actual extent of relative public influence.
- Modification: Public input is often channelled through explicit processes of deliberation and consensus building, thus running the risk of manipulation. Models such as A4R for example can be applied as a means of protection against unwelcome public challenge, rather than genuinely opening up decision-making to influence.

Approaches to engagement involving pre-defined mechanisms therefore run the risk of tokenism and manipulation, which in turn have an effect on the legitimacy of decisions (Williams et al., 2014). Incentivising citizens to take part under these conditions has proven difficult, not to mention the challenges of convincing citizens to sacrifice time out of their busy schedules to participate in priority setting processes.

To address these 'legitimacy' deficits a less prescriptive model of engagement might start not with the needs of the priority setting process—i.e. how we might get what we need and want from the public to help our decision-making—but with the expressed preferences and wishes of the public themselves. It is clear that under particular circumstances there are strong incentives for sections of civic society to become engaged in resource allocation decisions in health care. This may take the form of social movements, campaign groups and the 'contestatory' form of participation described by Slutsky et al. (2016). However, these forms of

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participation—which this paper argues should be conceptualized as meaningful modes of public and patient involvement—challenge mainstream models of priority setting as they do not accept a circumscribed role for the public, or presume a model of politics in which consensus building is seen as desirable. Furthermore, such forms of unsolicited engagement do not always or necessarily assume the legitimacy of limit setting, or the authority of the incumbent decision-maker to be the final arbiter. From a decision-maker perspective the gains made in voluntary and proactive public engagement are offset by significant loss of control over the decision-making process and consequent inability to place strictures on the rules of engagement. This has important implications for the decision-makers tasked with the management of health services.

In particular, if health service managers are the agents with delegated authority from principals, how does the practice of public participation complicate the understanding of who are the principals? In practice, since managers are normally appointed as a result of the exercise of political authority, a central element of their agency must be in relation to the politically authoritative or mandated principals who appointed them. In particular, they have a responsibility to manage budgets prudently and to allocate resources in a way that can be publicly accountable. However, unless public participation is to be merely tokenistic, they also have a responsibility to be responsive to the expressed preferences of public representatives. In effect, taking public participation seriously introduces a dual mandate into the authority structure of the manager.

It follows from this that, where there is a conflict between the mandated priorities derived from governments and the priorities expressed through active participation, the manager is in the position of having to balance contradictory demands or renegotiate the government mandated priorities. Such conflicts are endemic in priority setting, both in systems like that of England, where public participation in priority setting is institutionalized, and in systems like South Africa, Latin America or the Republic of Korea, where protest and demonstration have played a role in redefining priorities. The paradoxical result, however, is that, to the extent to which managers have freedom to balance or renegotiate priorities, public participation may increase, not limit, managerial discretion.

Managers must also exercise judgement as to the extent to which the public participation they encounter is representative of some broad current of opinion or

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3 interest. Patient groups often, and for quite understandable reasons, mobilize around
4 specific conditions or illnesses. However, there is every reason to expect that the
5 capacity for mobilization will vary from one condition to another, for example cancer
6 sufferers will find it easier to mobilize than those suffering mental health conditions.
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8 In the face of such differences, managers may well find that they have to exercise
9 discretion as to how weighty to treat particular public action. In such a situation it will
10 be tempting for managers and policymakers to retreat to an agreed public formula, for
11 example a QALY threshold expertly estimated, to determine what priority different
12 conditions call for. However, for patient representatives such a general formula may
13 simply seem to be a way of avoiding a discussion about the specifics of their disease.
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20 21 **Mapping the Research Agenda**

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24 It follows from the above discussions that the future research agenda on public
25 participation in health priority setting needs to take account of the importance of
26 democratic legitimacy and better representation (Weale et al., 2016). The conditions
27 under which public participation and priority setting exercises yield legitimate
28 coverage decisions in health are largely unmapped. However, before providing an
29 overview of the areas for future research, it is useful to draw on another discipline
30 from which insights on the role PPI have emerged, namely that of PPI in research, to
31 consider how these insights may relate to the research agenda that is advocated here.
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38 PPI in research and in priority setting operate in adjacent but linked ways,
39 which provides opportunities for learning between the fields. For example, the
40 concept of co-production is becoming increasingly important in health research. The
41 recent policy review from the National Institute for Health Research in England
42 identified the primacy of the concept of co-production, signaling the intention that
43 research knowledge should be produced collaboratively with the people it is intended
44 to benefit. Priority setting, especially its institutionalized forms such as health
45 technology assessment (HTA) bodies, is dominated by professionals and experts who
46 are the architects of the methods used for priority setting. This potentially limits the
47 ways in which the public can influence priority setting decisions which relates back to
48 the question of legitimacy. If the concept of co-production was drawn on to influence
49 priority setting, the public may be involved in designing or reviewing the methods
50 used for priority setting and there may be less need for protests and demonstrations in
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some countries. Given the very active public participation that is desired in priority setting—in research, participation usually denotes being a subject in a research study and is seen as more passive and a much less powerful form of involvement—drawing on the concept of co-production may prove beneficial. Vice versa, the articles included in this special issue highlight that public participation in priority setting benefits from a strong theoretical underpinning in democratic theory that drives development and provides clarity of intent. A similar theoretical approach would benefit PPI in health care research, which has been poorly theorized to date.

The emerging wisdom in priority setting is that involving the public can increase the chance of successful policy implementation by increasing the legitimacy of decision-making. This parallels debates in PPI in research that emphasize higher quality research that is relevant, acceptable and appropriate from a patient perspective (Staniszewska et al., 2011). The potential for involvement to impact on the implementation of evidence into practice is only just starting to emerge in thinking (Hunter, 2013; Staniszewska et al., 2013). Moreover, a recent RAPPORT study identified the vital role of relationships in developing successful forms of involvement (Wilson et al., 2015). In other words, the behavioural, but also the political features of relationships between participants and stakeholders in priority setting activities are likely to play an important role in determining the outcomes of participatory exercises.

The reflections provided here and throughout this article give rise to at least eight areas for future enquiry:

1. Under what conditions is legitimacy in priority setting generated and what is the role of the public in that process?
2. Equity of coverage decisions: What is the empirical relationship between public participation and fairness in health prioritization?
3. Modes of participation: Do different types of priority setting decisions warrant/require different types of participation? Can/do consensus and contestatory forms of public participation co-exist?
4. Principals and agents: Who is the ultimate guardian of the public good in priority setting?

5. Incentives: How can decision-makers be incentivised to take public engagement seriously? How can the public be incentivized to participate? Can priority setting ever secure public support?
6. Consensus building: Where are the boundaries between consensus building and encouraging active debate and disagreement? How can manipulation of views and processes to achieve a desirable outcome be avoided, or at least mitigated? What role do power relations play in consensus building exercises and participatory processes more generally?
7. How can structures be built, relationships nurtured and behaviours from decision-makers and stakeholders encouraged, that lead to meaningful participation practices in place of tokenistic forms of engagement?
8. New public management: What effect has public involvement had on the implementation of new public management policies, which often seek to replace what are essentially political processes requiring public debate with managerial processes (Hood, 1991; Dunleavy and Hood, 1994; Hood and Peters, 2004; Gruening, 2001)?

Conclusion

It is politically popular to involve the public in priority setting and, indeed, in any other aspect of health policy. To appear to be doing otherwise in the 21st century amounts to political suicide. We live in an age where politicians are expected to follow public opinion rather than to lead it. Views such as Loughlin's (1996) suggesting that there must be a query over how rational rationing can be when society may not in fact be rational are not in fashion. And yet there remain difficult questions about how serious policymakers are when it comes to public engagement and PPI in general. Do they really want and value engagement or do they want endorsement for their preconceived preferences? Is PPI largely symbolic or tokenistic or are its potentially disruptive properties to be positively welcomed and embraced?

As the contributions to this special issue demonstrate, PPI is subject to multiple interpretations, ambiguity and considerable diversity. Moreover, these features reflect different political and organizational contexts and cultures. Passive acquiescence may prevail at one end of the spectrum, especially in jurisdictions that enjoy a large measure of consensus and an absence of corruption, while at the other

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end of the spectrum groups assemble on the streets to protest and seek changes in policy. The empirical survey of public participation has revealed a wide variety of forms and types. However, it has also revealed persistent and pervasive ambiguities about what is meant by the term ‘public’ in discussions of public participation. Sometimes it means patients or users of services, sometimes citizens as potential users of services, and sometimes citizens in their capacity as citizens. Moreover, although we can speak of public participation, in practice it is always representatives of the public who participate. That in turn raises questions about the basis of representation, whether it is appointment by a public authority, as it is in many cases, or selection through a random process as with some mini-publics or some other basis of representation. It is even true of the forms of contestatory participation that characterize some policy systems.

There is nothing amiss about this variety. We should not expect one form of participation to be an ideal-type for all others. Public participation takes place in different and often messy contexts and actors in policy systems pursue different goals in relation to public participation. However, the variable forms of public participation raise questions about health service management. These questions are particularly pressing in relation to priority setting, where resources allocated to one set of patients or users may reduce resources for other patients or users.

While there may be a general view prevailing across different jurisdictions and polities that PPI is desirable and ‘a good thing’, in practice evidence of its true purpose, value and impact remains sparse. Much of the discussion centres on forms of engagement and processes to ensure effective participation but the degree to which policies actually change as a result remains less clear. One reason may be the difficulty of disentangling the various forces that might have contributed to a policy shift. PPI involvement may only be one among many factors and possibly not the most critical or instrumental.

The implications for policymaking of conflicting interpretations of what PPI stands for and entails are potentially profound. Yet their very complexity and often ambiguity, together with the potential threats that might be posed for the status quo were PPI to be truly effective, may suit the purposes of policymakers intent upon keeping things fuzzy and imprecise. Symbolic gestures in regard to forms of PPI, or what has been termed ‘engagement camouflage’ for decisions already taken

elsewhere (Lawson 2007), are unlikely to survive for long and will quickly become discredited.

Perhaps public participation, and its role in priority setting, is always going to be an imperfect quest. It is an example of an unwinnable dilemma of public policy that gives rise to complex moral dilemmas. At best in such a messy system, policymakers may satisfice (Simon, 1957) and muddle through elegantly (Hunter, 1997), a notion grounded in pragmatic sensibility that has much to commend it. At the very least, however, the view of what constitutes public participation in health priority setting needs to be broadened. All too often public participation, especially in the form of social mobilization and protests, is viewed as uncomfortable or portrayed as a lobbying activity by groups who possess the loudest voice, or the vastest resources. While these concerns are perfectly reasonable, policymakers should acknowledge that priority setting processes exhibit legitimacy deficits that are yet to be addressed. Enlargement of the concept of public participation to include informal, contestatory, and unconventional modes of engagement results in a myriad of complicated questions that need to be confronted by policymakers and researchers alike. For example, who determines whether the views brought forward in a given participatory activity should be considered and acted upon? What conditions and structures yield legitimacy to such decisions? These questions are difficult and complex. However, given the variety of forms that public participation takes, asking them is both necessary and overdue.

References

Abelson, J., Forest, PG., Eyles, J., Smith, P., Martin, E. and Gauvin, FP. (2003), "Deliberations about deliberative methods: issues in the design and evaluation of public participation processes", *Social Science & Medicine*, Vol. 57 No. 2, pp. 239-251.

Barrero, CEA., Crane, ES. and Ruíz, HC. (2012), "Defending the Right to Health in Colombia", *NACLA Report on the Americas*, Vol. 45 No. 2, p. 70.

Braveman, P. (2006), "Health disparities and health equity: concepts and measurement", *Annual Review of Public Health*, Vol. 27, pp.167-194.

Culyer, AJ. and Wagstaff, A. (1993), "Equity and equality in health and health care", *Journal of Health Economics*, Vol. 12 No. 4, pp. 431-457.

Daniels, N. and Sabin, J. (1997), "Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers", *Philosophy & Public Affairs*, Vol. 26 No. 4, pp. 303-350.

Dixon, J. and Welch, HG. (1991), "Priority setting: lessons from Oregon", *The Lancet*, Vol. 337 No. 8746, pp. 891-894.

Dunleavy, P. and Hood, C. (1994), "From old public administration to new public management", *Public Money & Management*, Vol. 14 No. 3, pp. 9-16.

Gruening, G. (2001), "Origin and theoretical basis of new public management", *International Public Management Journal*, Vol. 4 No. 1, pp. 1-25.

Habermas, J. (1994) *Justification and Application: Remarks on Discourse Ethics*, MIT Press, Cambridge.

Holm, S. (1998), "Goodbye to simple solutions: the second phase of priority setting in health care", *British Medical Journal*, Vol. 317 No. 7164, pp. 1000-1007.

Hood, C. (1991), "A Public Management for all Seasons?", *Public Administration*, Vol. 69 No. 1, pp. 3-19.

Hood, C. and Peters, G. (2004), "The Middle Aging of New Public Management: Into the Age of Paradox?", *Journal of Public Administration Research and Theory*, Vol. 14 No. 3, pp. 267-282.

Hunter DJ. (2013), "Getting knowledge on 'wicked problems' in health promotion into action", in Clavier, C. and De Leeuw, E. (eds), *Health Promotion and the Policy Process*, Oxford University Press, Oxford, pp. 131-153.

Hunter, DJ. (1997) *Desperately Seeking Solutions: Rationing Health Care*, Longman, London.

Johnston, M. (2006). 'Funeral march' protest against Herceptin ruling. *New Zealand Herald*, available at:
http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10393885
(accessed 22 March 2016).

Kieslich, K., Ahn, J., Badano, G., Chalkidou, K., Cubillos, L., Hauegen, RC., Henshall, C., Krubiner, C., Littlejohns, P., Lu, L., Pearson, S., Rid, A., Whitty, JA, Wilson, J. (2016), "Public Participation in Decision-Making on the Coverage of New Antivirals for Hepatitis C", *Journal of Health Organization and Management*, This issue.

Klein, R. and Williams, A. (2000), "Setting priorities: what is holding us back— inadequate information or inadequate institutions", in Coulter, A. and Ham, C. (eds.), *The Global Challenge of Health Care Rationing*, Open University Press, Buckingham, pp. 15-26.

Kwon, S. (2003), "Healthcare financing reform and the new single payer system in the Republic of Korea: Social solidarity or efficiency?", *International Social Security Review*, Vol. 56 No. 1, pp.75-94.

Lawson, N. (2007) *Machines, Markets and Morals: the new politics of a democratic NHS*, Compass, London.

Loughlin, M. (1996) "The language of quality", *Journal of Education in Clinical Practice*, Vol. 2 No. 2, pp. 87-95.

Matheson, D. and Loring, B. (2011), "Health inequities are rising unseen in New Zealand", *New Zealand Medical Journal*, Vol. 124 No. 1334, pp. 8-9.

Mitton, C., Smith N., Peacock S., Evoy B., and Abelson J. (2009), "Public participation in health care priority setting: a scoping review", *Health Policy*, Vol. 91 No. 3, pp. 219-228.

New Zealand Herald. (2010), "South Island neurosurgery reforms announced", available at:
http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10686633
(accessed 22 March 2016).

Oliver, A. and Mossialos, E. (2004), "Equity of access to health care: outlining the foundations for action", *Journal of Epidemiology and Community Health*, Vol. 58 No. 8, pp. 655-658.

Patient-Centered Outcomes Research Institute (PCORI). (2015), "Biographies – Advisory Panel on Addressing Disparities", available at: <http://www.pcori.org/get-involved/join-advisory-panel/advisory-panel-addressing-disparities/biographies-advisory-panel> (accessed 2 April 2016).

Pharmaceutical Management Agency (PHARMAC). (2016), "Consumer Advisory Committee (CAC)", available at:

<https://www.pharmac.govt.nz/about/committees/consumer-advisory-committee-cac/>
(accessed 2 April 2016).

Simon, HA. (1957) *Administrative Behaviour*, Free Press, New York.

Slutsky, J., Tumilty, E., Max, C., Lu, L., Tantivess, S., Hauagen, RC., Whitty, JA, Weale, A., Pearson, S., Tugendhaft, A., Wang, H., Staniszewska, S., Weerasuriya, K., Ahn, J. and Cubillos, L. (2016), "Patterns of Public Participation: Opportunity Structures and Mobilization from a Cross-National Perspective", *Journal of Health Organization and Management*, This issue.

Solomon M. (2015) *Making Medical Knowledge*, Oxford University Press, Oxford.

Staniszewska, S., Thomas, V. and Seers, K. (2013), "Patient and public involvement in the implementation of evidence into practice." *Evidence Based Nursing*, 10.1136/eb-2013-101510

Staniszewska, S. Brett, J., Mockford, C. and Barber, R. (2011), "The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research", *International Journal of Health Technology Assessment in Health Care*, Vol. 27 No. 4, pp. 391-399.

Weale, A. (2016), "Between Consensus and Contestation", *Journal of Health Organization and Management*, This issue.

Weale, A., Kieslich, K., Littlejohns, P., Tugendhaft, A., Tumilty, E., Weerasuriya, K. and Whitty, JA. (2016), "Introduction: Priority Setting, Equitable Access and Public Involvement in Health Care", *Journal of Health Organization and Management*, This issue.

Whitehead, M. (1992), "The concepts and principles of equity and health" *International Journal of Health Services*, Vol. 22 No. 3, pp. 429-445.

Williams, I., Phillips, D., Nicholson, C., Shearer, H. (2014), "Evaluation of a deliberative approach to citizen involvement in health care priority setting", *Leadership in Health Services*, Vol. 27 No. 1, pp. 5-19.

Williams, I., Robinson, S. and Dickinson, H. (2012), *Rationing in Health Care: The theory and practice of priority setting*, The Policy Press, Bristol.

Wilson, P., Mathie, E., Keenan, J., McNeilly, E., Goodman, C., Howe, A., Poland, F., Staniszewska, S., Kendall, S., Munday, D., Cowe, M. and Peckham, S. (2015), "ReseArch with Patient and Public involvement: a RealisT evaluation - the RAPPORT study", *Health Services and Delivery Research*, Vol. 3 No. 38. DOI: <http://dx.doi.org/10.3310/hsdr03380>